Association of Community Behavioral Health Authorities of Illinois (ACMHAI)

Comments on the 1115 Waiver
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For additional information, contact Dee Ann Ryan at dannryan5@aol.com or 217-474-3500

ACMHAI is the association representing the network of county, township and municipality behavioral health authorities across Illinois. Mental Health Authorities are statutorily charged with assessing, planning for and directing resources to support systems of care for residents of all ages needing mental health services, substance use disorder services and those with developmental or intellectual disabilities and Authorities for the Care and Treatment of Persons with a Disability have the specific focus on the needs of those with a developmental or intellectual disability. As funders, the behavioral health authorities distribute more than $60 million into community-based service systems in Illinois annually.

ACHMAI very much appreciates the opportunity to provide recommendations for inclusion in the state's 1115 waiver application. ACMHAI had previously submitted comments for the development of the Concept Paper for the waiver but we have since realized how significant this waiver can be for children's behavioral health toward resolving current issues and implementation of System of Care plans and we wish to add to our comments.

I. Current Issues in Illinois concerning Children's Behavioral Health and how the 1115 Waiver might be helpful:

1. **Costs of Out of Home Care for Children with Mental Health Issues:**
   In 2010, Illinois spent $382.5 million dollars on out of home care for children's mental health issues:
   - $149 million for acute psychiatric hospitalization paid by the Department of Healthcare and Family Services (HFS);
   - $200 million for residential costs for Department of Children and Family Services (DCFS) wards, which are offset by Federal Financial Participation from both Title IV-E and Medicaid;
   - $17.5 million paid by ISBE for the educational costs for students in residential placements who are diagnosed as SED (Serious Emotional Disturbances); and

- $16 million for children and youth placed residentially through the Individual Care Grant Program, (ICG), which is a financial grant to assist parents/guardians to obtain residential placement or intensive community-based mental health services.

❖ **1115 Waiver Strategy**-

An expanded array of Medicaid allowable services approved through a waiver would decrease hospitalization and residential costs as families would have access to respite and other home and community supports. A special workgroup under the Illinois Children's Mental Health Partnership has been working to define an expanded service array and has identified the following services as critical to an adequate continuum of community based care-

1. Care Coordination – Wraparound approach
2. Parent and Youth Peer Services
3. Parent Support and Training
4. Intensive In-Home Services
5. Respite Services, In-home and Out-of-Home
6. Mobile Crisis Response and Stabilization Services
7. Residential Crisis Stabilization
8. Therapeutic mentoring
9. Transition Services

Several of the above cannot be provided as Medicaid billable services unless they are approved through a waiver.

2. Litigation Regarding Children with Behavioral Health Issues

- According to a presentation Dr. Lori Jones made to the Medicaid Advisory Council (MAC) meeting, there is growing pressure from litigation related to residential care for Medicaid youth. The litigation involves 12 Illinois youth who were placed in out-of-state residential care at a cost of $1.5M in 2012. (More were placed in 2013 and several of the children have been "stuck" in the out of state placements due to lack of step down services.)
- Currently, there is a Class Action lawsuit filed in the Federal Court of the Northern District alleging failure to comply with the mandates of the Medicaid Act, the Americans with Disabilities Act and the Rehabilitation Act and there are several similar lawsuits filed in Federal Court of the Central District for individual children.
- Psychiatric Residential Treatment Facilities (PRTFs) are the only Medicaid allowable residential treatment for children with a mental health disorder. There are no PRTFs for children in need of mental health treatment in Illinois. To complicate matters, Illinois also has a limited home and community based service system. Therefore, the majority of children with severe emotional and behavioral issues are being placed out-of-state. In the Central District lawsuits are being court ordered into expensive, far from home, out- of-state, PRTFs. Some children are being placed as far away as New Mexico and Wyoming. Once a child has been placed in a PRTF, there is a lack of step down services so the

child cannot be discharged or transitioned back into their community or if discharged cycle back to residential treatment for the same reason.

- **1115 Waiver Strategy**

A similar class action suit (*Rosie D. v. Romney*) occurred on January 26, 2006 when a judge ruled that Massachusetts violated EPSDT by failing to provide various intensive community-based mental health services, including comprehensive assessments, case management and clinical oversight, and in-home behavioral health services necessary to maintain a child at home or in the community. (Rosie D. v. Romney, No. 01-30199-MAP, January 26, 2006). Massachusetts' remedy services are financed through an 1115 waiver.
Many other states have HCBS waivers for children with behavioral health disorders which allow states to claim federal match for essential home based services and to waive:

- Limits on the amount, duration and scope of Medicaid services, thereby enabling the state to offer specialized intensive HCBS not available through mandatory or optional Medicaid services or through other state or county programs
- Parental deeming requirements, thereby providing access to intensive mental health services for youth who might not otherwise be financially eligible for Medicaid
- Statewide requirements, allowing the state to implement the waiver in particular geographic areas

3. Custody Relinquishment Issues

There are growing numbers of families feeling that they have no other choice but to relinquish custody of their children in order to access appropriate mental health services. Private insurance coverage is unavailable or inadequate and family income exceeds the limits for public programs. Moreover, private insurance plans do not cover the full array of intensive, community-based rehabilitative services that children with the most severe mental or emotional disorders need. Children often enter the child welfare or juvenile justice systems in an effort to access treatment. In the past few years this has led to an increasing number of children with mental illness becoming psychiatric lockouts and or being placed in the child welfare or juvenile justice system, less than therapeutic environments.

- **1115 Waiver Strategy**

Expanding the array of home and community based services would help families maintain children in their homes, including those children who have been adopted within the state system as they have Medicaid. While Illinois has been generous about enrolling children in Medicaid, many children with serious mental illnesses or emotional disturbances are not able to get the mental health services they need because their parents do not qualify for Medicaid and they have

private insurance which often does not cover the services needed to maintain children in their homes. Because wards of the state are entitled to treatment, parents who cannot get this care for their child often times quit their jobs in order to enroll in Medicaid or they turn to the child welfare system (relinquishing custody). Intensive community-based mental health services as well as time-limited community based crisis respite with a focus on family-directed care and family reunification should be included in in the 1115 waiver application as a "Tefralike" waiver (I.e. Katie Beckett Waiver). This waiver allows children Medicaid coverage who would be eligible for Supplemental Security Income (SSI) because of their disability by waiving the family income limits and allowing the child to become a family of one. Some states have instituted family cost sharing with these waivers which still allow the children to receive home and community services without bankrupting the family. There would be significant savings since the child will not become a ward who would likely live in an institution and would not have a positive adult prognosis.

4. Individual Care Grant (ICG) Issues and Workgroups

The Individual Care Grant (ICG) program was established by Public Act 76-1943 in 1969. The Act was established to provide financial subsidies to parents or guardians of children with severe mental illness to assist them in obtaining the appropriate level of treatment services (residential or in-home/community). The management and oversight of the ICG Program is the responsibility of the Child & Adolescent Services Division of the Department of Human Services' Division of Mental Health (DHS-MH).

In recent years, the ICG Program has come under increasing criticism for a variety of reasons. Families and stakeholders have consistently reported that the application process is too complicated, cumbersome and lengthy. Similarly, families and stakeholders have complained that the eligibility requirements are too narrow and do not adequately provide access to ICG services for all the children and families who need them. Additionally, there is widespread misperception across child-serving systems that children must be declared ineligible for the Individual Care Grant before they can access other residential services. Finally, families and stakeholders have complained about the decreasing number of approved ICG applications. Of equal concern is the increasing length of stay for children in residential ICG treatment and delays in transitioning them back to their families and community-based treatment services. DHS-MH has committed to revising Rule 135 and restructuring the ICG Program through five workgroups, one of which will deal with ICG Levels of Care & Community Infrastructure.

- **1115 Waiver Strategy**

The waiver strategies detailed in previous sections such as adding home and community based services which are not allowable through Medicaid without a waiver such as respite and family support and deeming of parental income in a Katie Beckett like waiver would ultimately make it possible for many of the

children whose parents feel they have no alternative than to apply for an ICG and place their child residentially to keep them at home and allow the state to receive federal match for more Medicaid services as opposed to non-reimbursable residential costs, child welfare and juvenile justice involvement.

II. WORKFORCE DEVELOPMENT

ACMHAI recommends including workforce development dollars in the DSRIP bonus payments be utilized to train paraprofessionals to carry out home and community based direct support to children and families. As part of the continuum of care, direct support is one means of providing mental health services in the children's natural environment and preventing unnecessary out-of-care placements of children with serious emotional and behavioral disorders. This direct support service is individualized, one-on-one assistance and supervision for young people in order to achieve one or more predetermined treatment goals. During the development of the Illinois United for Youth SAMHSA grant, training modules were developed to influence the implementation of training and utilizing direct support staff to assist youth in their homes and communities with this essential service. New York State Mental Health has developed extensive training for direct support staff which they have named Skillbuilders in their Children's Mental Health Waiver which is available for use in Illinois. Workforce development and training funds would help Illinois implement a deliberate strategy to expand this pool of paraprofessionals who would work under the supervision of licensed staff to expand the capacity of the home and community based workforce.

Thank you for allowing ACMHAI to add these suggestions for the 1115 Waiver plan. We believe that a healthy Illinois begins with emotionally healthy children and that those with disorders should be allowed to receive treatment in their homes, schools and communities.